Advanced Practice Nurse Specialization in Adult Congenital Heart Disease

DNP Final Project

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By

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Abstract

Background: The population of adults with congenital heart disease (ACHD) is one of the fastest growing segments of patients in cardiology. Although the incidence of congenital heart defects remains stable, the probability of survival of these infants to adulthood is now at least 90%. In 2005 the estimated number of ACHD exceeded the number of children with congenital heart disease for the first time in history. Approximately 400, 000 ACHD have moderate or complex disease that requires lifelong care by providers specialized in ACHD. The number of ACHD-specialist providers is relatively small and until recently no formal training programs existed for physicians; none exist now for advanced practice nurses (APNs). Purpose: The purpose of this narrative study was to describe the knowledge and skills identified by current APNs in a pediatric hospital as requisite to caring for ACHD. The findings from this study contribute to a foundation from which to develop a specialty training program for APNs to develop competence in caring for ACHD. Methods: A qualitative design with a focus group interview was used with the population of APNs in The Heart Center at Nationwide Children's Hospital in Columbus, Ohio. These APNs practice in the inpatient, critical care, procedural, and outpatient areas. They all have had to learn to manage ACHD without benefit of formal training in ACHD. The interview guide derives from the question: "What do you now know that you wish you had known when you began to take care of adults with CHD?" Data were analyzed using content analysis techniques to identify themes and patterns. Results: Participants identified knowledge of comorbidities, medications, and institutional resources as essential. Essential skills included active listening and critical thinking. Analysis of the participants' discussion of their experiences caring for ACHD in a children's hospital revealed three themes: complexity, multidisciplinary team, and divergent needs. Conclusions: Findings from this

project suggest that an educational program for APN specialization in ACHD should facilitate strong interpersonal skills and critical thinking. Knowledge should be broad-based to include both physical and psychosocial domains. The program should foster interdisciplinary collaboration.

Background

Advances in medical and nursing care of children born with congenital heart defects have led to the expectation that 90% of children born with a congenital heart defect today will survive into adulthood (Moons, Bovijn, Budts, Belmans, & Gewillig, 2010) and lead satisfying and productive lives. Adults with congenital heart disease (ACHD) are one of the fastest growing populations in cardiology (Gatzoulis, Hechter, Siu, & Webb, 1999; Wren & O'Sullivan, 2001). In 2005, the estimated number of ACHD (>1 million) in the United States exceeded the number of children living with congenital heart disease (623,000) for the first time in history (Marelli, Mackie, Ionescu-Ittu, Rahme, & Pilote, 2007).

Unfortunately most ACHD who need specialized care for their CHD are not receiving that specialized care (Dore, de Guise, & Mercier, 2002). Research has indicated that 75 to 90% of these high risk patients are not receiving specialized cardiac care-- if any care at all-- after reaching adulthood (deBono & Freeman, 2005; Mackie, Ionescu-Ittu, Therrien, Pilote, Abrahamowicz, & Marelli, 2009; Wacker et al., 2005; Yeung, Kay, Roosevelt, Brandon, & Yetman, 2008). The consequences of not receiving specialized care can be disastrous. Even with early childhood repair of their heart defect, some ACHD may be up to 100 times more likely to die suddenly than age-matched control patients (Silka, Hardy, Menashe, & Morris, 1998). For ACHD who have had a lapse of care of 5 years, the likelihood of needing urgent hospitalization or invasive treatment is increased 10 fold compared to those patients who had ongoing care (Wacker et al., 2005; Yeung et al., 2008). Among the reasons for lapse of care is lack of access to appropriately trained and educated providers.

The urgent need for the ACHD population is for both physician and non-physician adult-focused CHD specialty providers (Child et al., 2001). As early as 1973, Perloff recognized the evolution of congenital heart disease, calling for a new specialty of adult congenital heart disease. Despite increased attention from national consensus statements (Child, et al, 2001) the great need for physician and non-physician providers with expertise in adult congenital heart disease remains. The Adult Congenital Heart Association (2010) convened a national strategic initiative called Vision 2020 that strives to create a comprehensive and organized system of care for ACHD. Among the objectives of Vision 2020 is the estimation of workforce needs and recommendations for meeting those needs. The importance of developing an expanded and competent workforce to care for the ACHD population cannot be understated.

However great the need it is essential that workforce development proceed with a thoughtful and comprehensive approach. Planning for workforce development must consider not only the kinds of providers (e.g. physician, advanced practice nurse, registered nurse) but also the requisite competencies for each discipline as well as how the competencies will be developed and measured. Such a plan must be comprehensive in that it addresses issues such as resource allocation: How many ACHD are needed to support a tertiary center? What level of technological sophistication is needed at a local level? Most important a plan must involve all stakeholders: patients, families, providers, payers, and policy makers.

Although there are published guidelines for physician preparation in care of ACHD, there are no existing guidelines for preparation of nurses and nurse practitioners in that specialty. Advanced practice nurses (APNs) who currently care for ACHD have had to learn informally on the job primarily under the guidance of physician partners; there have not been a significant number of experienced APNs to educate incoming APNs about ACHD. The lack of any formal

education program about ACHD has caused these APNs- many of whom are pediatric APNs-to essentially be thrust into the situation of managing ACHD despite their preparation and certification to care for children.

The APRN Consensus Work Group and the National Council of State Boards of Nursing APRN Advisory Committee published a joint statement (2008) describing a model for APRN regulation. APNs currently are educated at the graduate level and prepared for one of four roles: nurse practitioner, clinical nurse specialist, nurse midwife, or nurse anesthetist. They primarily focus on a particular population: neonatal, pediatric, adult, family, or women (APRN Consensus Work Group, 2008). As APNs increasingly participate in specialty care, they must either learn on the job or find a willing mentor-- often a physician-- in order to acquire the knowledge and skills required for specialty practice. Limitations of either approach are the lack of standardized content, inconsistent assessment of knowledge and skills, and variability in the expertise of the mentor (Alexandrov et al., 2009). This model illustrates the current pathways to APN practice (Figure 1) and also clearly indicates that specialty training and education are beyond the structure of APN preparation—and instead are delegated to the domain of professional specialty organizations to establish competencies and certifications (Figure 2).

Alexandrov and colleagues (2009) described the first APN fellowship program in the United States. The Neurovascular Education and Training in Stroke Management and Acute Reperfusion Therapy (NET SMART) fellowship, which focuses on acute stroke care, is an academic program modeled after physician fellowship programs and is internet-based with a centralized clinical validation practicum at the end.

The NET SMART fellowship has as its primary goal the development of "…a critical mass of APNs capable of providing neurovascular clinical practice leadership that results in improved tPA treatment rates and patient and hospital outcomes" (Alexandrov et al., 2009, p. 441).

Alexandrov and colleagues viewed the NET SMART fellowship as a template for postgraduate fellowship in other disciplines. They noted, "Faculty and institutions capable of providing specialty-level APN programs [should] take on this charge to promote evidence-based content and …further the role APNs play…for years to come" (Alexandrov et al., 2009, p.448).

The problem that drives this project is insufficient access to appropriate specialty care for ACHD. Creating an education and training program for APNs in the care of ACHD may be one way to increase the supply of specialty providers prepared to address the complex needs of this growing population. The program can be modeled on the NETSMART program.

Project

The purpose of this narrative study was to describe the knowledge and skills identified by APNs currently caring for ACHD at Nationwide Children's Hospital Heart Center. At this stage in the research knowledge and skills are generally defined as those aspects of care provision that are specific to caring for adult patients with CHD contrasted with caring for children with CHD. This project strove to identify the knowledge and skills needed by APNs caring for ACHD through a series of focus group interviews with APNs currently managing ACHD in the setting of a free-standing pediatric hospital.

This study used a qualitative approach because the issue-- requisite knowledge and skills for APNs caring for ACHD-- is not defined and requires exploration. Creswell (2007, p. 39) stated one of the characteristics of qualitative research is "…a focus on learning the meaning that

the participants hold about the problem or issue, not the meaning that the researchers bring to the research or writers from the literature." The information about requisite knowledge and skills may be found in the stories of the APNs who provide care to ACHD without benefit of a formal training program.

Focus group interviewing is a qualitative technique that facilitates a greater understanding of the topic by capturing themes and details not readily acquired through observation or fixed survey (Krueger, 1994). The dynamic of the focus group creates synergism among the participants by stimulating recall of additional dimensions of the experience under discussion (Morgan, 1988; Stewart, Shamdasani, & Rook, 2007). The technique of focus group interviews is especially useful when exploring the needs and perspectives of health care teams (Coté-Arsenault & Morrison-Beedy, 1999; Morrison & Peoples, 1999; Sharts-Hopko, 2001). The focus group technique is a natural fit for this project because the participants--APNs involved in ACHD care-- already are part of a larger health care team providing care for ACHD patients. As experienced clinicians with in-depth experience ("content expertise") in the central topic explored in focus group interviews, their expertise can inform the development of a future education program for APNs who wish to focus their practice on ACHD.

Research Questions

1. What are the knowledge and skills identified by current APNs in a pediatric hospital as essential to caring for ACHD?

2. What are the experiences of APNs caring for ACHD in a pediatric hospital?

Conceptual Framework

The theory guiding this project is Action Learning as described by Morgan and Ramirez (1984). Action learning is "both a concept and a form of action that aims to enhance the capacities of people in everyday situations to investigate, understand, and if they wish, to change those situations in an ongoing fashion with a minimum of external help" (Morgan & Ramirez, 1984, p.9). Action learning promotes understanding through reflective action and emphasizes that understanding must guide one's actions as well as explain the situation. Action learning strives for seven qualities (Morgan & Ramirez, 1984):

1. To be democratic and heterarchical (heter: different; arch: lead or rule): no one knows it all; we learn from each other. In the context of the focus group the cumulative learning about caring for ACHD is greater than the information obtained from any one person.
2. To be pluralistic: acknowledge the value of various perspectives
3. To be proactive and empowering
4. To link individual and social transformation: "Think globally, act locally"
5. To integrate different kinds and levels of understanding
6. To create conditions that are always evolving and open-ended
7. To demonstrate its worth in terms of the capacities it creates for intelligent action rather than terms of its contribution to formal knowledge.

Framing this project in the context of action learning leads to the following applications. The focus group is a forum that capitalizes on the qualities of action learning. Focus groups excel in articulating knowledge from each participant's perspective- knowledge that is not

necessarily shared among all participants and arises from various kinds and levels of understanding. The focus group is intended to create a dynamic and open-ended condition in which the participants' responses synergize.

Future projects will expand upon the findings of this project and include input from clinicians, educators, ACHD patients, and administrators. Those participants would be recruited from the Columbus Ohio Adult Congenital Heart (COACH) program, Nationwide Children's Hospital, The Ohio State University College of Nursing, and The Ohio State University Medical Center. The diversity of these participants acknowledges the value of their various perspectives on the process and content of educating future care providers for ACHD and captures the strength of their collective wisdom. Capitalizing on this diversity the vision is an educational program for APNs that is rich in knowledge and experience, promotes intellectual agility, and fosters a sense of responsibility to self, program, community, and the ACHD population. The educational program would be informed by the qualities of action learning-- especially the qualities of heterarchy, pluralism, linked individual and social transformation, and the creation of capacities for intelligent action.

Methods

IRB Approval

The Institutional Review Board at The Ohio State University approved this project. Risks to participants were related to self-disclosure in a group of peers. The possibility existed that individual experiences or opinions could be shared outside the focus group despite the moderator's admonition to maintain privacy. Most participants were pediatric nurse practitioners; the fact that they are caring for adult patients may expose a vulnerability to a

question of practicing beyond their credentialed scope of practice—a question that has not as yet been addressed at the regulatory level.

Design

The study used a qualitative design with a focus group interview. There are no reports in the literature on this topic. A qualitative research design was well suited to this project because of the exploratory nature of the study in that the knowledge obtained by the APNs through their experience is complex and not adequately described by a quantitative survey design. In addition the focus of qualitative research is on achieving depth of understanding rather than breadth.

The design of qualitative research is emergent and follows inductive reasoning through the iterations of the data collection and analysis. Emergence means that the study design, research questions, and methods can evolve even as data collection and analysis occur iteratively, because the meaning attributed by the individual to their experience is highly dependent on the context of the experience. Furthermore the reality of one person (the investigator) is not the reality of the subjects; therefore the design cannot derive from only one person's reality or perspective and must address the constructs of others' realities (Lincoln & Guba, 1985).

Accessible population. This study focused on the insights of APNs in The Heart Center at Nationwide Children's Hospital in Columbus, Ohio. There were 15 APNs working in different areas throughout the Heart Center including cardiothoracic ICU, cardiothoracic surgery, interventional cardiac catheterization laboratory, inpatient step-down unit, and cardiology clinics. These participating APNs brought substantial content expertise to the discussion based upon their experiences participating in the care of the ACHD population at Nationwide Children's

Hospital during a period when the presence of ACHD patients has grown from a rarity to a routine encounter. Twelve of the APNs are Pediatric Nurse Practitioners, two are Adult Nurse Practitioners, and one is a Family Nurse Practitioner. These APNs were selected purposefully for this study because of their experiences in caring for ACHD patients in the various clinical areas within the setting.

Inclusion and exclusion criteria. Advanced practice nurses working in the Heart Center at Nationwide Children's Hospital were eligible to participate in this study. APNs having a position of reporting authority over other APNs in the Heart Center were not eligible for participation.

Setting

Nationwide Children's Hospital is a free-standing facility in Columbus, Ohio. It currently has over 300 beds. The organization has committed itself to lifelong care of its patients with chronic disease that begins in childhood thus extending the organization's impact beyond the comprehensive care of children in primary care and acute care settings. The Columbus Ohio Adult Congenital Heart Program at Nationwide Children's Hospital is one of the largest ACHD programs in the United States and admits nearly all of its patients needing surgery or cardiac catheterization procedures to Nationwide Children's Hospital. A recent review of care of ACHD at Nationwide Children's Hospital (Crumb et al., 2011) identified 782 patients undergoing 1,490 procedures or non-elective admissions from 2002 through 2007. The number of patients per year during the study period showed steady growth. Thus the APNs at Nationwide Children's Hospital Heart Center have experienced a growth in the number of adults with congenital heart disease under their care.

Procedures.

Recruitment. Eligible APNs were invited to participate through an email invitation (Appendix A). Because the potential participants are all colleagues of the principal investigator (SC), all contact regarding study participation was with a faculty member (LD) at the College of Nursing. The intent of this strategy was to minimize any perception by the potential participants of obligation or coercion. The invitation included the purpose of the study, the format of the study, the dates and duration of the focus groups, risks and benefits of participation, and contact information. A scripted telephone call from the faculty member followed the invitations within 1 week of the email to provide an opportunity to answer questions and secure participation (Appendix B). A reminder telephone call from the faculty member took place the day before the focus group (Appendix C).

Interview. To facilitate maximal participation three focus groups consisting of 3-5 participants each were scheduled to be conducted at Nationwide Children's Hospital in a conference room. The focus group interview was scheduled for a 2 hour time period with established questions to guide the exploration and discussion (Appendix D). An investigator experienced in moderating facilitated the focus groups. In addition to the facilitator, a co-moderator was present to record the process of the interview, noting such things as tone of voice, body language, or level of animation (e.g., thoughtful pauses versus rapid-fire responses) and to present a summary of key points of the discussion at the end of each focus group. Participants provided written informed consent prior to the beginning of the interview (Appendix E).

The focus group was audio-recorded and transcribed by a professional transcriptionist. The focus group moderator verified the accuracy of the transcription and the de-identification of

participants. The digital recording of the focus group was erased after verifying the transcriptions. The faculty would contact the focus group participants within 1 week following the focus group interview to offer them an opportunity to share any additional thoughts. A summary of the themes and patterns identified from the focus group data was mailed to participants; participants were invited to send comments within 7 business days addressing the adequacy and accuracy of the data interpretation (Appendix F).

Data Analysis. The focus group data was analyzed using content analysis (Carney, 1972; Creswell, 2007; Krippendorff, 1980). Goetz and LeCompte (1981) described a spectrum of analytical techniques along four dimensions: (a) deduction-induction, (b) generation-verification, (c) construction-enumeration, and (d) subjective-objective. Qualitative data are most amenable to analysis by techniques at the inductive-generative-constructive-subjective end of the spectrum. Glaser and Strauss (as cited in Lincoln & Guba, 1985) promoted the technique of constant comparison for analysis of qualitative or naturalistic data. Constant comparison "combines inductive category coding with a simultaneous comparison of all social incidents observed. As social phenomena are recorded and classified, they also are compared across categories" (Goetz & LeCompte, 1981, p. 58). Lincoln and Guba (1985), again citing Glaser and Strauss, noted that constant comparison is a "continuously developing process" (p. 340). Accordingly preliminary analysis of data from each focus group will occur before the next focus group is conducted.

The process of data analysis began with the co-moderator's verbal summary of the major points of the discussion at the end of the focus group; participants were asked to comment on whether the summary accurately and completely reflected the key points of the discussion. After the conclusion of the focus group the moderator and co-moderator debriefed each other. This

debriefing was focused on the group dynamics and whether there was evidence of individual dominance, reluctance to respond to any questions, or disagreement with the verbal summary of the focus group discussion. Following transcription of the data the moderator reviewed the data and compared it with the original recording for accuracy.

The principal investigator is an APN in The Heart Center at Nationwide Children's Hospital with over 15 years of experience working with ACHD. He has contemplated developing a post-graduate educational program for APNs who wish to focus their practice on ACHD. Because of his intimate familiarity with ACHD and thoughts about what would go into an educational program, he recognized a risk of bias in data analysis of this project. To promote integrity of the data analysis another faculty member (RC)—whose areas of expertise are public health and qualitative methods—also coded the data.

After receiving the transcript and debriefing summary the investigators immersed themselves in the data by multiple readings of the transcription. The next step in analysis was coding of the data. Coding is the association of labels to common ideas or concepts that appear in the narrative. Codes were both in-vivo (emerging from the words of participants) and in-vitro (pre-determined by the investigator) (Creswell, 2007). Coding was applied initially to the data at multiple levels--called units of analysis (Krippendorff, 1980)--by coding words, phrases, and sentences. Later rounds of coding considered the level of the entire participant comment, Data saturation could not be evaluated because only one focus group occurred.

Enhancing rigor. Qualitative rigor is the means to establish trustworthiness or confidence in the results of qualitative inquiry (Lincoln & Guba, 1985; Thomas & Magilvy, 2011). There are four components of qualitative rigor: credibility, transferability, dependability,

and confirmability. The techniques used in this inquiry to enhance credibility included prolonged engagement in the setting by the principal investigator, investigator triangulation, and member checks. The principal investigator has been in practice at the site of inquiry for more than 4 years, which is sufficient time to gain appreciation and understanding of the setting. The second investigator was a doctoral committee member with expertise in public health and qualitative research. This investigator was closely involved at all stages of the project. Member checking is the process of verifying the accuracy of the investigator's interpretation with the participants. This verification occurred at the conclusion of the focus group interviews and by inviting participants' comments to written summaries after data were analyzed. However, no comments were received.

Transferability addresses the question "How can one determine the extent to which the findings of a particular inquiry have applicability in other contexts or with other subjects?" (Lincoln & Guba, 1985, p. 290). The description of the time and context of the qualitative inquiry enhances its transferability. The qualitative investigator must provide a dense or thick description of the population, time, and setting (context) from which someone else may draw their own conclusions as to the applicability of the study to their own context (Thomas & Magilvy, 2011).

Results

There were three focus group opportunities from which potential participants could choose. No participants responded for the first two sessions prompting a fourth session at a different time. Ultimately only one focus group with four participants took place.

The third and fourth participants arrived later and separate from each other. The moderator and co-moderator observed that the first two participants often agreed with each other, whereas the third and fourth participants brought slightly different perspectives. The focus group participants did not appear to have any issues of dominance or discomfort with individual questions. All participants contributed actively to the discussion. All participants agreed that the verbal summary of the discussion presented by the co-moderator at the conclusion of the focus group was accurate and complete.

The first research question explored essential knowledge and skills for APNs caring for ACHD. The areas that emerged were knowledge of "adult" comorbidities, medications, advanced cardiac life support algorithms (ACLS), and institutional resources such as adult medicine consult service and ACHD team. One participant observed:

> Sometimes, when you're used to working in a pediatric facility, then you're not really accustomed to taking care of adults and knowing what the comorbid conditions are. So just having more experience with that and trying to update yourself on the medications because they're changing so much, and we keep getting newer ones out. But also knowing where your resources are to look for that info too.

Another participant commented:

> And when I say resources, I mean making better use of the adult congenital team, involving them in their management of care and the patients, involving them in discharge planning. They should also take advantage of the adult congenital team in terms of education.

The areas related to skills were higher level skills: active listening and critical thinking. Technical skills were not considered unique to caring for adults or children, although the ease of performance of those skills could certainly vary between adults and children. Participants' responses exemplified these skill areas:

> Listening. You have to be able to listen to your adult patient to hear the whole picture. Yes, they're having a medical problem, but how is it affecting everything else

> Critical thinking—just familiarizing yourself with what kind of best care and testing that the adult patients require—being up to date on that kind of information because it keeps changing. It's a very big, growing field

> In terms of skills actually in the ICU—I mean, if there will be things like chest tube placements, intubations, arterial lines, centrals lines— those techniques are fairly standard across the age range so I don't think that there's any specific things that would be different.

Research Question 2 explored the experience of APNs in a children's hospital caring for ACHD. Data analysis revealed three dimensions related to providing that nursing care: complexity, team, and divergent needs of children and adults with CHD.

Participants described several domains of complexity. The anatomical abnormalities of the original heart defect and the subsequent repairs were emphasized strongly. One participant stated:

> My first adult congenital heart disease patient was kind of my first exposure to congenital heart disease because I came from an adult world. I was just floored by what kind of anatomy that they actually had.

Participants also described the medical complexity of ACHD related to comorbidities such as hypertension, dyslipidemia, diabetes mellitus, nicotine abuse, or coronary artery disease. The participating APNs recognized that psychosocial issues added complexity to the ACHD patients: issues of limited family or social support, difficulty finding or maintaining employment, and the perception by the APNs that ACHD experienced a form of medical abandonment. The following participants' comments illustrate these aspects of complexity:

> Not only the medical issue, you're dealing with social, financial, a lot of other factors. So I think it's more involved [with adults]

> They're more complex, and they don't have a parent helping them often times.
>
> I actually felt bad for the patient because I asked the patient what he did for a living. And he said that he's tried to work in several fast food places, and he just didn't have the energy to stand up all the time, especially when it's busy.
>
> These are a cohort of patients that are complex patients that typically or historically pediatric institutions have not wanted to care for once they turn 18, so many of them have been lost to follow-up out in the community and or are not receiving proper cardiology follow-up care.
>
> They [ACHD] often times come with comorbidities because they're kind of abandoned out in the community.

Participants placed a high value on the presence of a multidisciplinary team when caring for ACHD. In part the multidisciplinary team assured that resources were available to meet the varied needs of ACHD. But there was also a role for the team to support the APNs through ongoing education in caring for ACHD. When asked, "Do you think that there's a benefit to ACHD patients being seen in a pediatric facility verses an adult facility? Or is it really the team in place for either facility that makes a difference?" participants responded

> It's the team
>
> It's definitely the team
>
> The surgeon, the interventionalist, the cardiologist, the nurse practitioner, someone from billing, someone from administration
>
> And that's partially for knowledge and partially to cover our license.
>
> And we can also get a consult with Adult Med because they a lot of times have thoughts and things that we just don't think of—because that's what they do.

The dimension of divergent needs (ACHD compared to children with CHD) reflects recognition of differing developmental issues in adulthood, different physical plant and

equipment needs, and different dynamics in ACHD patient-family interactions. Participants commented:

> Cannot treat an adult patient with congenital heart the same ways you treat a pediatric patient—with different life challenges and different needs.
>
> *logistic* just like bedside commodes that are big enough and the appropriate size blood pressure cuffs particularly for obese patients, some bariatric beds. We have a Hoyer lift, we have a larger bathroom
>
> I think the thing that I always think about whenever I work with an [adult] don't have a lot of support and so they don't think anything and then they just start feeling horrible. So I think the issue of follow up should be families from day one
>
> Just to be familiar with caring [for] the separate needs of a pediatric versus an adult patient. And also having more of a multidisciplinary approach to an adult patient's care.

Participants were asked what advice they would offer to someone planning an educational program for APNs to specialize in ACHD. Their responses included:

> It's like you can't just give nurse practitioners a couple pieces of advice. They really need to kind of immerse themselves into our system and see how we run the whole program.
>
> Just to be familiar with caring [for] the separate needs of a pediatric versus an adult patient. And also having more of a multidisciplinary approach to an adult patient's care.

Discussion

Adults with congenital heart disease are a rapidly growing segment of cardiovascular care. The population is complex not only because of their underlying heart defects but also because the repairs available to treat the defects are in constant evolution. The patient born with transposition of the great arteries in 1960 has a very different repair than an infant born with the

same defect in 1990 and since. Consequently the long-term issues for each patient are different. In fact, the long-term issues for the child born in 1990 are unknown as those children are just now reaching adulthood.

In 1973 Dr. Joseph Perloff anticipated the evolution of congenital heart disease from a strictly pediatric concern to a predominantly adult issue. In 2005 that vision was realized as the number of ACHD exceeded the number of children with CHD. At the time of the 32nd Bethesda Conference on the Care of Adults with Congenital Heart Disease, the task force on workforce issues reported "the physician workforce caring for ACHD patients in the U.S. consists of a few (< 20) adult cardiologists with advanced training, as described, and an ongoing career focus in ACHD, as well as a much larger number of adult and pediatric cardiologists with little or no specific training in the care of ACHD patients, but with on-the-job experience" (Child et al., 2001, p. 1187). As part of the proposed response to this severe shortage the Task Force recommended "Training programs for other key staff (e.g., nurses, physician assistants, psychologists, social workers, other non-physician personnel) on ACHD teams should be established" (Child, et al., 2001, p.1187) in addition to physician training programs. Thus there is a call for APNs to specialize in ACHD. To date, no such APN training programs exist.

As described above, the principal investigator is an APN with over 15 years' experience in the field of ACHD and has contemplated what an educational program for APNs in ACHD might include. Using investigator triangulation minimized the opportunities for the data to be interpreted according to the principal investigator's perspective. Because one model of care of ACHD takes place in children's hospitals, it is important to understand the experiences, challenges, and insights of the APNs who practice in a pediatric setting. These APNs routinely

attend to both children and adults and can provide a unique perspective on the knowledge and skills that are essential to caring for ACHD.

This project used qualitative focus group methodology to describe essential knowledge and skills needed by APNs caring for ACHD through a qualitative approach using focus group interviews. The guiding questions explored the APNs' perception of knowledge and skills both explicitly and implicitly through inquiry about the APNs' experiences. The focus group questions were intended to address two research questions: *What are the knowledge and skills essential to ACHD?* and *What is the experience of APNs caring for ACHD in a free-standing children's hospital*?

The participating APNs identified knowledge of comorbidities and medications as well as knowledge of institutional resources as essential to caring for ACHD. The APNs reported active listening and critical thinking as essential skills; they did not report any unique, age-specific technical skills.

Three dimensions emerged from the APNs' discussion of their experiences caring for ACHD. The first dimension—complexity--involved several domains ranging from the anatomy of the heart defect to the presence of comorbidities and the psychosocial issues that challenge many ACHD. Particularly striking was the perception by the APNs of medical abandonment of ACHD relating to the lack of ACHD providers and the refusal of many pediatric hospitals to care for these patients after age 21. The second dimension--multidisciplinary team-- reflected the APNs' conviction that excellent patient care required a broad array of perspectives, knowledge, and skills. The multidisciplinary team dimension included two domains: comprehensive patient care and education of staff. The third dimension was divergent needs. The APNs recognized that adults are not "big children" and therefore have their own set of developmental,

psychosocial, and educational needs. Examples of divergence of adults from children with CHD also took on more tangible forms such as appropriately sized equipment and supplies.

The principal investigator,--being both clinician to ACHD in The Heart Center and investigator for this project--anticipated that participant responses would describe specific knowledge and skills as requisite to caring for ACHD. From his perspective the participants' responses about knowledge and skills essential to caring for ACHD were both expected and surprising. Expected responses included knowledge of comorbidities and medications. Somewhat surprising was the near absence of any discussion of anatomy and physiology, surgical repairs, sequelae of repairs, etc. Participants' emphasis on listening and critical thinking was unexpected.

An important finding of this project is the role of institutional commitment and multidisciplinary team in the provision of ACHD care. The participants' emphasis on the importance of institutional commitment is congruent with the principal investigator's observations that successful ACHD programs have strong institutional support. This finding also supports the Doctor of Nursing Practice competencies that state quality effective APN care has system as well as multidisciplinary collaboration implications.

The findings from this project suggest that an educational program focused on preparing APNs for specialty practice in congenital heart disease should address multidisciplinary collaboration. The educational experience should include a strong experiential component that facilitates development of effective interpersonal skills and critical thinking. The knowledge base should be broad—addressing not only physical but also psychosocial aspects of the ACHD experience. Preparation of both APNs and as physicians with expertise in ACHD may alleviate

the abandonment of ACHD perceived by the APNs participating in this project by increasing access to appropriately trained and educated providers.

Strengths

This project is believed to be the first to explore and report the experiences of APNs in a free-standing children's hospital caring for ACHD. Although only one focus group took place there was active involvement by all participants. There was confirmation of the dimensions identified among the participants as well as by the member check at the end of the focus group. Coding was strengthened by the use of investigator triangulation.

Limitations

The results of this project must be interpreted with caution due to the limited number of participants and only one focus group. Therefore neither data saturation nor confirmation of hypotheses that might have occurred across focus groups could be addressed. The participants in this project came from the same pediatric hospital with an established adult congenital heart disease program: The participants may not perceive the same knowledge and skill needs as APNs in a different setting. Future studies will need to explore the transferability of these findings.

Future Directions

This project has identified several areas for further exploration. Implications of the growing ACHD population for health care organizations, the health care system, and health care workforce training in the United States deserve investigation. Service gaps of ACHD have multiple causes—exploration of these factors would be consistent the objectives of Healthy People 2020 (USDHHS, 2012). The perception of medical abandonment described by the participants needs to be explored with other provider groups and especially among ACHD.

Exploration of ACHD perceptions about their care in terms of access and adequacy will be valuable to inform future developments in health care system structure and policy.

The aims of this project, to determine the knowledge and skills needed to care for ACHD, will be further explored with APNs in other settings including both children's hospitals and adult hospitals. Another investigation will explore the perception of other providers about the knowledge and skills of APNs caring for ACHD. The findings of these investigations will inform and support APN training and program planning.

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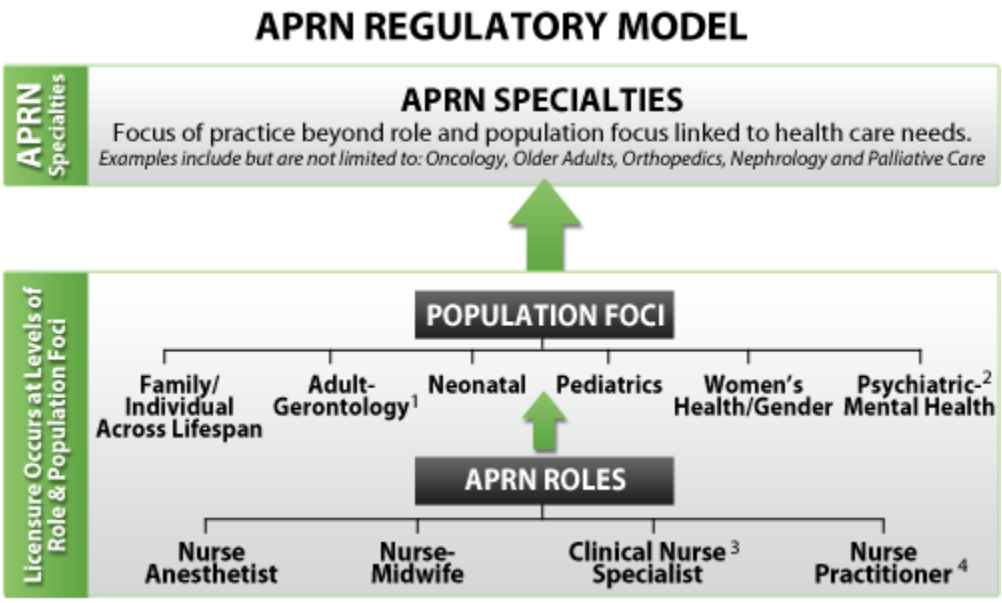
Figure 1. Consensus Model for APRN Regulation



Notes:

[1] The population focus, adult-gerontology, encompasses the young adult to the older adult, including the frail elderly. APRNs educated and certified in the adult-gerontology population are educated and certified across both areas of practice and will be titled Adult-Gerontology CNP or CNS. In addition, all APRNs in any of the four roles providing care to the adult population, e.g., family or gender specific, must be prepared to meet the growing needs of the older adult population. Therefore, the education program should include didactic and clinical education experiences necessary to prepare APRNs with these enhanced skills and knowledge.

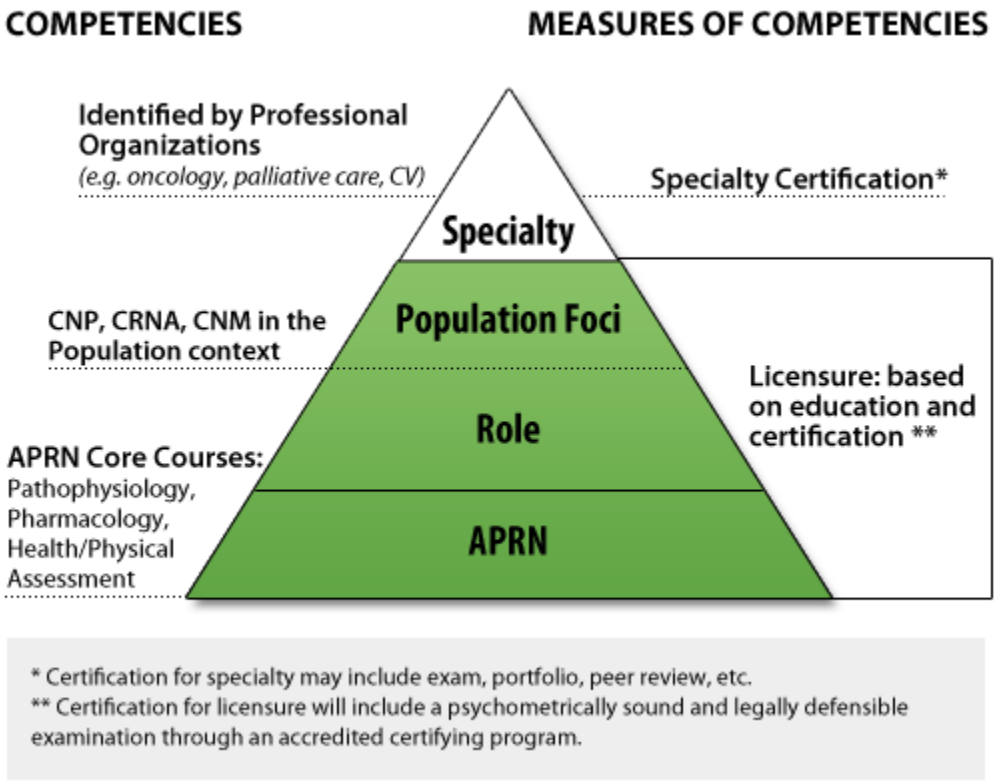
[2] The population focus, psychiatric/mental health, encompasses education and practice across the lifespan.

[3] The Clinical Nurse Specialist (CNS) is educated and assessed through national certification processes across the continuum from wellness through acute care.

[4] The certified nurse practitioner (CNP) is prepared with the acute care CNP competencies and/or the primary care CNP competencies. At this point in time the acute care and primary care CNP delineation applies only to the pediatric and adult-gerontology CNP population foci. Scope of practice of the primary care or acute care CNP is **not setting specific** but is based on patient care needs. Programs may prepare individuals across both the primary care and acute care CNP competencies. If programs prepare graduates across both sets of roles, the graduate must be prepared with the consensus-based competencies for both roles and must successfully obtain certification in both the acute and the primary care CNP roles. CNP certification in the acute care or primary care roles must match the educational preparation for CNPs in these roles.

APRN Consensus Work Group (2008)

Figure 2. Consensus Model for APRN Regulation



APRN Consensus Work Group (2008)

Appendix A

Invitation to participate in a study

Your experience is valuable!

Participate in a research study.

Share what you have learned as an APN caring for adults with congenital heart disease.

If you participate in this study, you will:

- Join 3-5 other APNs who care for adults with congenital heart disease in a focus group interview that will last about 2 hours
- Participate in the focus group discussion by sharing your experiences and what you have learned about caring for adults with congenital heart disease

We will keep all data collected confidential

Location of study: Nationwide Children's Hospital

To take part in this research study or for more information, please contact 614-292-8222

Appendix B

Telephone Script

Hello, my name is (NAME). I am an administrative assistant at the Ohio State University College of Nursing. I am assisting Dr. Linda Daley and Stephen Crumb in research to learn more about what advanced practice nurses in the Heart Center at Nationwide Children's Hospital believe is important knowledge and skills for caring for adult patients with congenital heart disease. Did you receive the informational email inviting you to participate?

(if yes, proceed; if no, ask if they would be interested in learning about the study.

If interested, continue; if not thank them for their time and end the call).

If you participate in this study, you will:

- Join 3-5 other APNs who care for adults with congenital heart disease in a focus group interview that will last about 2 hours
- Participate in the focus group discussion by sharing your experiences and what you have learned about caring for adults with congenital heart disease

Your participation in this study is voluntary. This means that you do not have to participate in this study unless you want to. Would you be willing to answer some questions to help determine if you are eligible for this study?

Good. I will read a list of questions.

1. Are you an advanced practice nurse in the Heart Center at Nationwide Children's Hospital?

   Y N

2. Have you been in this role for at least 4 years? Y N
3. Do you hold a supervisory role over other APNs in the Heart Center? Y N

(Subject is eligible if the answers are 1. Yes, 2. Yes, and 3. No. If subject is <u>not</u> eligible, thank them for their time, say they are not eligible and end the call. If they are eligible, proceed).

The purpose of this research study is to learn more about the experiences of advanced practice nurses in a pediatric hospital who care for adult patients with congenital heart disease. Another purpose is to find out what these APNs think is important knowledge and skills for an APN to have in order to care for adults with congenital heart disease. We estimate that about 15 APNs will participate in this study. You will be asked to join 3-5 other APNs in a focus group interview. The focus group will take about 2 hours of your time. During the focus group you will be asked to talk about your personal experiences of caring for adults with congenital heart disease. The discussion will be tape recorded to avoid missing anyone's comments. There is a small chance that some of the questions may make you feel uncomfortable. You don't have to answer those questions if you don't want to. In fact you don't have to answer any question that you choose not to answer. And that is fine.

All the information you provide, including your name, will be strictly confidential. In fact all names will be deleted and replaced with artificially created IDs in the transcription of the tape. No names will be attached to any comments in reports of the study. Your comments will remain confidential. There will be no way to identify individual participants.

The only risk to you might be some discomfort discussing your experiences in front of your colleagues or if your comments were ever shared by another focus group member. There are no other expected risks to you for helping with this study. There are also no expected benefits for you either.

Do you have any questions?

Are you interested in participating in this study?

Can we set up a focus group time?

Thank you for your interest in this project.

You can contact Dr. Daley at (614) 292-4928 for any questions about the research study. All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

Appendix C

Reminder Script

Hello, my name is (NAME) at The Ohio State University College of Nursing. I am calling to remind you of the focus group you are scheduled to attend tomorrow at (TIME) in (ROOM) at Nationwide Children's Hospital. Thank you for participating. We look forward to seeing you.

Appendix D

Interview Guide

Thank you for agreeing to participate in this focus group discussion about caring for adult patients with congenital heart disease in a pediatric hospital. You were each invited to participate in this study because you are advanced practice nurses who work at Nationwide Children's Hospital and take care of adult patients with congenital heart disease. We want to hear your experiences, thoughts, and feelings about caring for adult congenital heart patients here.

Today we will be discussing your experiences in caring for adult patients in a pediatric hospital. We want to know what is good, not so good, and what you think is important to your ability to care for adult congenital heart patients.

Before I ask you to read and sign the consent form, let me highlight a few points in the consent. This discussion is part of a research project to understand the requisite knowledge and skills for caring for adults with congenital heart disease. Your participation is voluntary. You may choose to stop participating at any time. If you decide to stop participating there will be no penalty. There is no direct benefit for you to participate in this study. The only risks are those of personal disclosure. It is possible you may feel some discomfort discussing your experiences or feelings about certain experiences. Are there any questions? (Answer questions) Please read and sign the consent form. (Co-moderator name) will collect your signed form.

Before we begin, let me suggest a few things that will make our discussion more productive. Please speak up, but only one person at a time. If you have a cell phone, please either turn it off or set it to vibrate. We are tape recording the discussion so we don't miss any of your comments. During the discussion we will be on a first name basis but all names will be deleted and replaced with artificially created IDs in the transcription of the tape. No names will be attached to any comments in reports of the study. Your comments will remain confidential. Even though we will keep this information confidential, we all need to respect each other's privacy and keep what is said here in the discussion confidential: You should not say anything here that you would not want to be repeated, even inadvertently, outside this room.

Each of you has received a copy of the questions for this discussion. I will be moving the discussion from one question to the next. It is important that we hear from each of you because you each have a different experience. In order to hear from everyone and to keep us on track for time I may limit some discussion or I may encourage people who haven't spoken up to do so.

Opening	Tell us your name and where you work
Introduction	When you hear the words "adult congenital patient" (ACHD), what comes to mind?
Transition	How do you compare the ACHD population and the pediatric congenital heart population?

Transition	Think back to one of the first times you took care of an adult congenital heart patient here: What was that experience like?
Key	What are the challenges or difficulties in taking care of ACHD patients in a pediatric facility? (Can you give an example?)
probe	What knowledge do you think is essential to care for ACHD patients? How did you acquire that knowledge?
probe	What skills do you think are essential to care for ACHD patients? How did you gain those skills?
Ending	I'm going to wrap up our discussion with some ending questions. First, I'd like each of you to share in one sentence what was the key thing that you heard tonight about APNs caring for ACHD. What is the main piece of advice would you give to someone developing a program for APNs to specialize in adult congenital heart disease? My last question before (CO-MODERATOR NAME) gives us a summary of the discussion, is—is there anything we didn't discuss that we should have or anything I didn't ask that I should have—to help us get a good understanding of the requisite knowledge and skills for caring for ACHD patients.
Co-moderator summary	(NAME) is going to give us a summary of the discussion. As she is reading the summary, please note if there are any things you would like to clarify or any additional information you want to add to anything we discussed here this evening.
Final	Is there anything else you would like to add?
Closing	Thank you for your time and participation in this discussion. You will be receiving a follow-up telephone call from our administrative assistant asking if anything occurred after you left here tonight that you would like to share. You will each receive a copy of the summary of our analysis of tonight's discussion within 2 weeks. Please review this and return it with any comments: Does the summary reflect what you believe was discussed? Is there anything you want to add or clarify?

Appendix E

Consent Form for focus group participation

The Ohio State University Consent to Participate in Research

Study Title: Advanced practice nurse specialization in adult congenital heart disease

Researcher: Linda Daley, Ph.D. and Stephen R. Crumb, MSN

Sponsor: N/A

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose: The purpose of this narrative study is to describe the knowledge and skills identified by current advanced practice nurses in a pediatric hospital as requisite to caring for adult patients with congenital heart disease.

Procedures/Tasks: You will join 3-5 other people in a focus group interview. During the interview you will be asked to share your experiences and what you have learned about caring for adults with congenital heart disease.

Duration: The focus group interview will last about 2 hours.

You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University or Nationwide Children's Hospital.

Risks and Benefits: There is no direct benefit for you to participate in this study. The only risks are those of personal disclosure. It is possible you may feel some discomfort discussing your experiences or feelings about certain experiences.

Confidentiality:

All names will be deleted and replaced with artificially created IDs in the transcription of the interview. No names will be attached to any comments in reports of the study. Efforts will be made to keep your study-related information confidential. However, there may be circumstances

where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;

Incentives: There are no incentives for participating in this research. Light refreshments are provided at the focus groups.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:
For questions, concerns, or complaints about the study you may contact **Linda Daley, PhD. The Ohio State University College of Nursing, (614) 292-4928_**.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact **Linda Daley, PhD. The Ohio State University College of Nursing, (614) 292-4928__.**

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

Printed name of subject	**Signature of subject** **AM/PM** **Date and time**
Printed name of person authorized to consent for subject (when applicable)	**Signature of person authorized to consent for subject (when applicable)** **AM/PM** **Date and time**
Relationship to the subject	

<u>Investigator/Research Staff</u>

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent	**Signature of person obtaining consent** **AM/PM** **Date and time**

Appendix F

Letter to invite comments on the summary

Dear Participant,

Thank you for your contribution to the focus group **Advanced practice nurse specialization in adult congenital heart disease**. The investigators have completed their analysis of the data. A summary of the themes and patterns that emerged from analysis of the comments is attached. The investigators would appreciate your review of the summary and your comments about the accuracy and completeness of the themes and patterns. Please respond in the context of your individual experience and your recollection of the discussion in your focus group. Kindly return your comments in the enclosed self-addressed envelope within 7 days.